



SPINAL COURIER

SPINAL CORD
COMMISSION

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New VISTA Volunteers Arrive

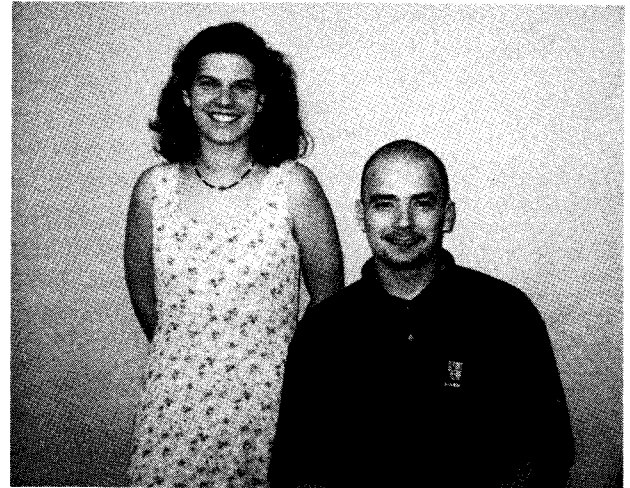
Since 1993, the Spinal Cord Commission has had the opportunity to work with the Corporation for National Service through the Volunteers In Service To America (VISTA) program. These volunteers work on specific projects here at the Commission, building our capacity for new services and developing new projects and programs. Over the years, the Commission has benefited from the services of these individuals.

In July, two new VISTA volunteers joined the Commission.

Jenni Friedberg is the new Education and Resource Center Coordinator.

Jenni's primary project this year will be development of the ASCC web page, to give our agency a presence on the Internet and to provide information and resources on spinal cord injury and the Commission. She has already begun her assessment (*so please give her a hand by answering the questions on page 7*). In this capacity, Jenni is also responsible for keeping our resource library up-to-date and responding to your requests for materials. Jenni hails from

Continued on pg. 8 - see "New VISTAs"



ASCC Receives Grant Award

In Arkansas, on any given day, one in every five people with a spinal cord injury has a pressure sore. Studies show that pressure sores, also known as decubitus ulcers, bedsores or pressure ulcers, are one of the most severe secondary conditions that result from spinal cord injury. They are also the most expensive. A hospitalization for pressure sores averages \$54,000 - \$92,000.

In an attempt to help individuals prevent pressure sores, the Spinal Cord Commission is teaming with the Centers for Disease Control (CDC) on a three year prevention project. The CAPPS (Consumer Action to Prevent Pressure Sores) project will provide in-home pressure sore prevention training to individuals at risk for pressure sores. This will include a comprehensive assessment by a medical team, followed by a training program developed by the individual with the team.

Continued on pg. 5 - see "ASCC Grant Award"



Linda Island, of El Dorado, **Bettye Brown** of Waldo and **Stan Pryor** of Magnolia (left to right) — who together have 80 years of experience with SCI — served on an experts panel at the Commission's first regional mini-conference, "Living With Spinal Cord Injuries: An Update," held at the Medical Center of South Arkansas in El Dorado on September 26.

SPINAL COURIER

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BUCKLE UP!

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

Injuries Incurred Post-SCI: Unusual Burn Injury

Dear Editor:

We all know that SCI or other spinal cord disability leaves an individual more susceptible to other injuries and certain secondary conditions. However, one of my clients incurred an unusual burn injury that I thought everyone could learn to avoid. This individual was riding as a passenger in a car for an extended period of time on a hot summer day with her shoes off. The floorboard of

the car got so hot that she received a severe burn requiring extensive medical attention. It is always good practice to wear shoes for a number of reasons and burn avoidance can now be added to the list.

Robert Griffin
ASCC Case Manager
Russellville, AR

Readers Please Note:

If you have ideas on how to prevent post-SCI injuries, please send them in and we will print your ideas in this column. Thanks.

The Editors

From The Director

Early one morning, a young man walked along a beach upon which many starfish had washed during the night. In the distance, he could see an old man walking toward him. The old man paused often and bent down to pick up a starfish and toss it into the sea. When they finally met, the young man asked the old, "Why do you waste your time? There are hundreds of starfish stranded on the beach and you cannot possibly save them all. What does it matter if you save one here and one there?" In answer, the old man bent again, lifted a starfish and threw it into the sea. "It matters to that one," he said.



I borrowed this story from Keith Vire, Executive Director at Family Support Services in Fayette-

ville. The story is always on their newsletter and I am always struck by how much it means to me. Partly because the beach is my very favorite place, but mostly because I believe that the best way to help people is one person at a time.

We are all unique, with different needs, interests, resources and abilities. Some of us need a lot of help, others just a push or an idea now and then. The challenge is to figure out who needs what, when and how. It may take a little longer that way, it may take a little more communication, or a few more resources, but the end result, doing something *that matters to that one* is definitely worth it! Like the folks at Family Support, that is how I see what we do here at the Spinal Commission, making a difference, one life at a time.

One person who has made a difference here at the Commission is leaving this month. **Betty Massey** has worked in the Commission's Central Office for 19 years and is retiring this month. Betty has been my right hand person since I have been here and, with her long experience, I have always depended on her for a "historical perspective." She has made sure that our staff got their paychecks each month and she has sorted through the maze of insurance for many of us. Most importantly, Betty has coordinated Spina Bifida Camp every summer and assured that hundreds of you got to go to Camp! Like the man in the starfish story, Betty has touched many of our lives, one person at a time. We appreciate all that she has done, thank her for her support and wish her great fun in retirement!

Cheryl L. Vines

With Thanks

ASCC accepts tax deductible donations. The generosity of the many individuals and families who over the years have made memorial donations is greatly appreciated. Contributions are

used to assist our clients through purchases of equipment and educational resources.

If you would like to make a contribution, please contact the Commission at **501-296-1788 / 800 459-1517 / TDD 501-296-1794** or send your donation to:

AR Spinal Cord Commission
1501 N. University, Ste. 470
Little Rock, AR 72207

Donations This Quarter From:

Mr. & Mrs. Jerry Walker
Ms. Doris Ruff

Alternatives for Adults with Physical Disabilities

For many years, persons with disabilities have been concerned about how they would get the care they needed if family members were not available. In the past, nursing homes were the only solution for some people. Now the state is offering a program to allow these people to remain in their homes by providing them with up to eight hours of attendant care each day.

This was a concern of **Joe Buehrle** and his family. Joe sustained a C-4 spinal cord injury at the age of 18 and has remained in his parents' home since that time, with his mother providing almost all of his care. Their questions about "who will take care of Joe when we are not physically able to do so?" have now been answered. Since Joe would have no choice but to go to a nursing home if his parents could not care for him, he was delighted to hear about the

Alternatives program from his ASCC Case Manager. He applied and was approved. Now he is able to hire an attendant to come in and relieve his mother. It is his responsibility, as the consumer, to hire and train the person(s) to care for him. Those persons are considered self-employed and must send their time sheets, signed or marked by the consumer, to Alternatives. They will then be paid directly by that program.

To be eligible to apply for this Medicaid waiver program, a person must be between 21-64 years of age. (Elderchoices provides similar services for persons 65 and over.) Needs must be equal to intermediate level nursing home placement and must cost less than a nursing home patient. The waiver also provides for some modifications to the home which are



Alternatives program recipient Joe Buehrle with his ASCC Case Manager Martha Henderson.

necessary to ensure the health, welfare and safety of the consumer. The waiver program is a service of DHS Aging and Adult Services.

Persons who meet the eligibility requirements may call **1-800-981-4457** and request an application packet. ☺

Arkansas Technology Revolving Loan Fund Current Interest Rate 5%

The Arkansas Technology Revolving Loan Fund now makes financing available to Arkansans with disabilities and their family members to purchase assistive technology and related services. Acts 384 and 579 of the Arkansas Legislature recognize that adaptive equipment is often essential in order to find a job, maintain employment or to live more independently.

The current interest rate is 5%, which is well below the rate for conventional consumer loans. By law the Revolving Loan Fund is for loans, not grants or stipends. Therefore, applicants must demonstrate credit worthiness

and must have discretionary income available to pay back the loan. A co-signer can be used to help qualify for a loan.

Loan amounts may range from \$250 to \$10,000 and must be used to purchase assistive technology. For instance, a wheelchair lift for a van or hand controls can be financed, but not a van or automobile. Computer access adaptive devices may be financed, but not necessarily a computer. The fund is "revolving," meaning that money from repayment goes back into the fund and is used to make additional loans. The loan fund provides an avenue to help fill the gaps for purchase of

assistive technology that is not provided by insurance or other sources. Applications are consumer responsive and are available in accessible formats upon request. An application fee of \$10 must accompany the loan application.

For additional information or application forms, please contact:

Howard Harper
ICAN
2201 Brookwood Drive
Suite 117
Little Rock, AR 72202
501-666-8868 (Voice/TDD)
800-828-2799
501-666-531 (FAX) ☺

Medicaid Expands Durable Medical Equipment to Adults

The Arkansas Legislature made a great step during the 1997 legislative session when they directed the Department of Human Services (DHS) to expand durable medical equipment services to adults. Since 1991, the Arkansas Medicaid Program (a division of DHS) has provided durable medical equipment, including wheelchairs (and repairs), cushions, electric beds, walkers, bathroom equipment and assistive technology, by physician prescription, to qualified Medicaid recipients under the age of 21. Effective on July 1, 1997, this program was expanded to qualified Medicaid recipients over age 21.

For the first time in many years, Arkansas adult Medicaid recipients will be able to obtain needed durable medical equipment through Medicaid. These services must be medically necessary and prescribed by the individual's at-

tending physician. Those services with a cost exceeding \$500 will require a prior authorization by Medicaid before purchase. This may mean a delay (anticipated to be 2-3 weeks) before the equipment can be ordered.

So, how will Medicaid recipients access these services? Through their local durable medical equipment provider who is an Arkansas Medicaid provider. The individual should visit his or her physician to obtain a detailed prescription and medical justification of what is needed. In some cases, such as for specialized wheelchairs, an Occupational or Physical Therapist or Rehabilitation Specialist may be needed to do an evaluation and prepare a prescription for the physician's approval and signature. The individual would take the prescription to his local Medicaid provider (medical equipment

supplier) to obtain the equipment. The provider will then submit the request for payment to Medicaid. Purchases may only be made through official Arkansas Medicaid providers. If you have questions about what equipment and services are covered under the program, your provider is probably your best resource.

This is an exciting new program, which will provide much needed services to many people in Arkansas. It will very likely be the difference for allowing some folks to stay in the community, not in nursing homes.

Like all new programs, we can expect to feel a few "growing pains." Medicaid Director Ray Hanley and Assistant Director Roy Jeffus have done a super job in getting this new program

Continued on pg. 6 - see "Medicaid"

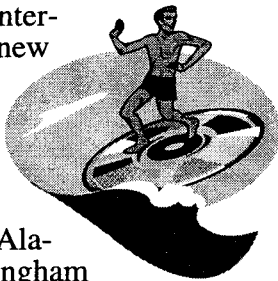
New SCI Information Web Site

For people who have access to the Internet, there is a new way to obtain information on spinal cord injury (SCI). The University of Alabama at Birmingham (UAB) recently launched a web site dedicated to SCI, the SPINALCORD Injury Information Network, which can be found at:

www.spinalcord.uab.edu

This web site indexes hundreds of items from recognized centers, organizations, researchers and educators. You can also post and read messages in the Guest Book or "talk" with others in the Chat Room.

The Arkansas Spinal Cord Commission is especially excited by



the web site because it includes 20 of our fact sheets, including:

- Heterotopic Ossification in SCI
- Preventing Pressure Sores in SCI
- Heat Tolerance in Quadriplegics
- Common Urological Problems: Leakage Around a Catheter
- Common Urological Problems: Frequent Catheter Changes
- Foley Catheter Care: Urethral or Suprapubic
- Attendant Care Services
- Female Sexuality and SCI
- Male Sexuality and SCI
- Bowel Management in SCI
- Predicting Outcome (Prognosis) in SCI
- Arachnoiditis
- Friedrich's Ataxia
- Selecting a Rehabilitation Center

- Management of Urinary Tract Infections in SCI
- ASCC Wheelchair Purchasing Guidelines
- Disabled Parking License Plates and Placards
- Autonomic Dysreflexia
- Syringomyelia
- Vibrator Technique for Ejaculation: One Person's Experience

You can locate these fact sheets by selecting the "Site Contents" option after entering this web site. There are two ways to find specific information. One is to use the alphabetical listing of terms or a topic list of items related to SCI.

Be sure to visit UAB's SPINALCORD Injury Information Network the next time you need SCI resources and information!

Fractures and SCI

By Shirley McCluer, M.D., ASCC Medical Director

First, I would like to clarify a common misconception. A fracture is a broken bone and a broken bone is a fracture. There is no difference — they are two terms that mean the same thing!

Fractures in the legs are as much as 100 times more likely to occur in young men with spinal cord injury (SCI) than in the general population in the same age group. In the 1996 survey of all Arkansas clients with traumatic SCI conducted by the Spinal Cord Commission, 35 percent had experienced a broken bone since their spinal cord injury. Specific details were not asked, but the most common location was in the legs.

Arm fractures are usually treated the same as they would be in the able-bodied population. However, the effect on self-care activities during the healing phase can be devastating. It is essential that the doctor who is treating the fracture understands the type of activity that you use the arm for. Since arms are not usually expected to be weight-bearing, casts may be removed after three to four weeks. At this stage it will be okay to move the arm and possibly push a wheelchair, but the bone would not be healed well enough to do pushups. Each such vigorous activity should be approved by your doctor before trying it.

Fractures in the legs may occur with little or no trauma because of osteoporosis (weakness of the bone from disuse). For example: it is not uncommon to have a hip fracture just from turning in bed. In persons with no sensation in the legs, the diagnosis is often overlooked because of the absence of pain. A good rule to follow is: localized swelling in one

leg is a fracture until proven otherwise. The only symptoms may be increased spasticity, increased mobility of the leg or autonomic dysreflexia. A fracture of the hip is especially hard to diagnose because the local swelling may not be obvious.

Treatment of leg fractures in a person who does not walk is different from treating an ambulatory person. Physicians may be concerned about failure to heal because of the SCI. However, this is very rarely a problem. The traditional cast should **NOT** be applied in most instances because of the risk of pressure sores under the cast. No matter how good the person is at padding a cast, the risk is great for a patient who has no sensation.

All that is needed in fractures between the mid-thigh and the ankle is a "pillow splint" or some other type of well padded splint that can be removed for skin inspection at least daily. A "pillow splint" is made by taking a medium thick bed pillow, placing it lengthwise under the leg that is broken and wrapping the pillow and leg with an Ace bandage. It should not be tight enough to cause swelling of the foot and ankle below the splint.

ASCC Grant Award

Continued from page 1

The project will be conducted in 25 Arkansas counties.

"We are pleased and excited to be working with CDC on this project," said Cheryl Vines, ASCC Executive Director and Principal Investigator for the project. "This grant will give us the resources to try out the strategies that we believe can decrease the number

If a person has severe spasticity, it may be especially difficult to keep the bone ends in place until initial healing "glues" them together. This usually takes about three weeks. Splints should be discontinued as soon as possible in order to prevent loss of motion at the knee.

For further information on this topic, contact the Spinal Cord Commission. &

New Spasticity Clinic

Arkansas Children's Hospital has a new neurologist, **Dr. Terence Edgar**, who is a specialist in the management of spasticity. He has a clinic every Monday and will see patients of all ages (not just children). To schedule an appointment, call **501-320-1850**.

and severity of pressure sores in Arkansans with SCI."

The project will begin on October 1, 1997. Watch for progress reports in the *Spinal Courier*. In addition, ASCC is working with the Arkansas Department of Health on another CDC funded project to identify other secondary conditions that affect Arkansans with disabilities. &

An English Roll

By Michael Long

For ten days this summer my wife Marsha and I had the opportunity to travel to England, and I want to share our positive experience so that you, too, might be encouraged to stretch your boundaries a little. Now, I realize there are lots of disabled folks who travel to all parts of the world, but this article is for people like me who usually don't go where a visa is required. And since I am a T-3 para and weigh a half-dozen times more than Hulk Hogan, I was reluctant to travel outside of the United States for fear that little would be accessible, and the trip would be difficult and frustrating. I dreaded the airline transfers, as well as the nine-hour transatlantic flight — not my idea of a good time. We had flown domestically several times since my injury, still this trip seemed more daunting.

But after a deep breath, we drove to Dallas and caught British Airways directly into London's Gatwick airport. The tickets were purchased well in advance for the best price, and we flew economy class with bulkhead seats (we had thought about upgrading our seats, but for that the airlines wanted serious money). I put my Roho cushion in the seat and squirmed and shifted through two movies, two meals, eight-and-one-half hours of flight and no sleep.

Trevor Pollitt, the owner of Wheelchair Travel, Inc., met us at the airport with a Ford Transit van that had a wheelchair lift at the rear. (He also has other vehicles with hand controls, as well as providing driving tours of London. Having a driver in London is a very good idea because the traffic is insane. We were told London cabs are accessible, but the tube [subway] is not.) In Trevor's vehicles, you can go anywhere you want, even France or other European countries. In our case, Mar-

sha quickly learned to drive on the left side of the road and to give way (yield) to the right in "roundabouts." We logged about 980 miles in the south-central section of England.

Not everything was accessible, of course, but that did not detract from an absolutely wonderful adventure. Often accessibility might be via a plywood ramp or through some alternate entrance in a cathedral, and a few places were just plain inaccessible. For instance, the elevators that were installed in Windsor Castle for Queen Victoria late last century only had a 24 inch door, and only one of the decks was accessible on the great warship H.M.S. Victory, on which Lord Nelson commanded. One airport hotel's idea of an accessible room was it was on the first floor and there were no stairs to climb — but, they quickly made arrangements for us in a nicer sister hotel down the street. Some pubs had more than one step to negotiate or didn't have a lift, but remember we're talking about a country with many centuries of history where the average home is probably 150 years old, and commercial buildings may have been constructed centuries ago. These few specifics are the worst examples, but for the most part things were just fine and dandy. And, hey, there are also small upsides to being in a wheelchair, such as when we were whisked through customs and avoided the somewhat lengthy wait the other passengers had to endure.

The big picture is that a person simply cannot be any more awed looking at ancient Stonehenge, the changing of the guard at Buckingham Palace, magnificent Westminster Abbey or taking the ferry to the Isle of Wight whether they are standing on their feet or sitting in a wheelchair. So, I encourage you to



Adventurous travelers, Mike and Marsha Long, in front of the Tower Bridge in London, England.

go and do the things you want to do, the things you dream about but may be reluctant to attempt. Your adventure might be in this country or in this state, but whatever you do — **GO!** This summer's adventure was a nice boost to my self-esteem, and gave me renewed confidence and hope for the future. Do the same for yourself! ♪

Medicaid

Continued from page 4

organized in less than 90 days! They are adding thousands of new recipients to the program with thousands of additional purchases (estimated cost in the first year is 5 to 8 million dollars) with virtually no additional staff. The new policies are in place, but are being revised as we go to press. Therefore, expect some delays as the program gets up and running. Be patient (but stick with it!). In the end, it will be worth it: individuals will get the equipment that they need, which was not available before.

Your ASCC Case Managers are learning more about the program as information becomes available and should be able to assist you with questions and problems. ♪

USA Takes Silver

Wheelchair basketball at its finest was exhibited in Toronto August 17-24, 1997. Seven national teams competed in the First Junior Men's World Championship, coming from Australia, Canada, France, Germany, Great Britain, Poland and the United States. the players ranged in age from 15 to 22.

The US team had a strong tournament, winning five of their eight games, to capture the silver medal. Arkansan **Steve Tew** led the US team, scoring 142 points and pulling down 60 rebounds. Captain **Paul Shulte** of Michigan added 128 points and grabbed 39 rebounds. For their outstanding play, Steve and Paul were named to the All-Tournament Team. Head Coach **Law Shaver** from Minnesota was very proud of his team's accomplishments and enthusiastically commented, "magnificent tournament, good people."

The final standings of the teams in this exciting tournament were: Canada with the Gold medal, USA with the Silver and Australia took the Bronze. ♪

Agent Orange Survey Progressing . . . Slowly

In August, a survey regarding parental agent orange exposure was sent to all clients with spina bifida who were born after March 1, 1961. To date only about one-half of the surveys have been returned. **We need your survey.** Please return your survey if you haven't done so already! Even if you do not qualify for this program we need to confirm that fact. If you have misplaced your survey, you may respond by telephone by calling **Tom Farley** at **1-800-459-1517**. ♪

WOW Is For Kids

WOW or Winners on Wheels is an innovative program that prepares youth in wheelchairs for today's mainstreamed environment, developing their self-confidence and independence. Often described as a "cub scout" program for kids in wheelchairs, the Winners (kids who use wheelchairs) earn Wheels (badges) in six progressive Spokes (activities). There are 62 Circles (chapters) nationwide that meet twice a month and are supervised by the Pit Crew (adult volunteers) who serve as mentors to the youngsters on their "fun race through life."

There is one Circle in Arkansas that meets on the second and fourth Saturdays of each month at the Friendship Baptist Church in Sherwood. Sixteen youth between

the ages of 7 and 11 enjoy organized activities, arts and crafts, games, wheelchair sports and field trips. The Circle is led by **Emma Purifoy** who has been involved in WOW for the last two-and-one-half years. "Activities are tailored to the interests of each local circle and the favorite of the Sherwood group is field trips," said Emma. "We really could use volunteers to help with the trips and so forth."

If you know a child who would benefit from the WOW program in Sherwood or would like to serve as a volunteer to this group, call Emma Purifoy for more information at **375-7146**. If you would like to start a WOW Circle in your area, call **Julie Overton**, Program Director at **1-800-969-8225, ext. 0-1730#**. ♪

ASCC Web Page Survey

The Arkansas Spinal Cord Commission is in the process of developing a web page. But we can not do it alone. Please take the time to fill out this short questionnaire and return it to:

**ASCC Education and Resource Center
1501 North University, Suite 400
Little Rock, AR 72207**

Thanks so much for your help!

1. Do you have access to a computer? Yes _____ No _____
2. Do you ever use the Internet? Yes _____ No _____
3. If "yes", what is your primary use? _____
4. Would you use ASCC's web site? Yes _____ No _____
5. What topics should be addressed on the ASCC web site?
(check as many as are applicable)
SCI Statistics _____ Information on the ADA _____
History of ASCC _____ Relevant Current Events _____
Fact Sheets _____
Other _____

New VISTAs

Continued from page 1

Atlanta, Georgia. She is a recent graduate of Tufts University in Boston with a degree in psychology. Jenni plans to go on to medical school when she finishes her VISTA year and has already begun the tenuous med school application process! When she is not "surfing the 'Net" for the Commission, Jenni enjoys quilting, reading and softball.

Steve Tew has assumed the Equipment Recycling Center Coordinator position. Steve is responsible for the care and maintenance of the durable medical equipment that the Commission has available to loan our clients. This includes obtaining, repairing, assigning and tracking the loaner wheelchairs in the Center. Steve's major project this year is to develop a computer database of all equipment in the Center to allow us to monitor its use and make it available to clients (equipment is only available through the Case Managers). Steve is a North Little Rock native who attended ASU-Beebe before taking a year out for VISTA. An accomplished wheelchair athlete, Steve is a member of the Rollin' Razorbacks, competes in road racing and serves as an assistant coach to the Junior Rollin' Razorbacks.

Please join us in welcoming Jenni and Steve to the Commission. &

Rollin' Razorbacks 1997-98 Game Schedule

Dec. 6 - 7	Home
Dec. 20 - 21	Dallas, TX
Jan. 9 - 10	Home
Jan. 31 - Feb. 1	Las Vegas, NV
Feb. 13 - 15	Birmingham, AL
Mar. 6 - 7	Regional Tournament - TBA
Mar. 19 - 21	FINAL FOUR Nashville

*All home games played at Sylvan Hills High School in Sherwood, AR. For additional information, call **Harry Vines** at (501) 834-8513.*

Junior Rollin' Razorbacks 1997-98 Game Schedule

Nov. 14 - 16	MidSouth Regionals Hot Springs, AR
Nov. 22 - 23	Dallas, TX
Jan. 17 - 18	Somerset, NJ
Jan. 23 - 25	Carbondale, IL
Jan. 31 - Feb. 1	Chicago, IL
March	Junior Nationals - TBA

*For additional information, call **Doug Garner** at (501) 767-9185.*

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